CHAPTER 7: SURVEILLANCE AND RESEARCH

This Chapter summarizes on-going HIV surveillance and research activities and program evaluation efforts, how surveillance and research information are linked to the strategies in the plan, and recommendations for additional surveillance and research needed to enhance HIV prevention planning and evaluation in South Carolina.

1. Surveillance

Tracking the Epidemic

The Introduction section of Chapter 1 "Epidemiologic Profile" contains a detailed description of HIV/AIDS surveillance systems in South Carolina. DHEC carefully monitors the status of HIV/AIDS and other sexually transmitted diseases enabling providers to implement strategies in communities around the state based on our best understanding of the epidemic.

In order to monitor the HIV epidemic in South Carolina, state law requires physicians, hospitals, laboratories, and other health facilities to report diagnosed HIV infection and AIDS cases to DHEC. The information obtained from health care providers includes risk factors, age, sex, race and geographic location. Follow-up with persons diagnosed with syphilis and HIV infection is conducted by health department staff to provide partner notification, confidential testing and counseling services, treatment, and referral to medical and support services. Surveillance data are also used to plan and design prevention and care programs to target persons most at risk for sexually transmitted diseases and HIV infection.

Active surveillance activities include routine visits with hospitals and infectious disease physicians to identify cases and compete CDC case report forms; comparisons with other data sources such as death certificates, TB registry, and the AIDS Drug Assistance Program.

Most reports of HIV infection and AIDS are initially laboratory based. All laboratories who conduct business in South Carolina are required to report to the health department all HIV infection or AIDS diagnosis when serum, urine, or oral fluid specimen is positive by screening test (EIA antibody), confirmatory test (Western blot) or an HIV detection test (PCR nucleic acid test, including viral load). In January 2004, laboratories were required to report all CD_4 and viral load (VL) tests regardless of test results.

South Carolina also receives CDC funds for the Enhanced Pediatric Surveillance project that analyzes medical record and other data to evaluate the effectiveness of perinatal HIV prevention efforts. Staff analyze the proportion of HIV infected pregnant women who have knowledge of their serostatus prior to delivery, proportion of HIV infected women prescribed antiretroviral therapy during pregnancy, labor and delivery and neonatal period, proportion of HIV infected women receiving cesarean sections, and selected birth outcomes. Each case of pediatric HIV infection due to perinatal transmission is analyzed to determine which prevention step was missed in order to identify follow-up training, education, or protocol development to ensure no missed opportunity for prevention.

Evaluation of key surveillance performance measures indicates South Carolina's surveillance system meets or exceeds CDC's performance criteria for 3 of 4 indicators: timeliness of reports, completeness of reports, and accuracy (duplication). See Table 9.1 below.

Table 9.1 South Carolina HIV Reporting Performance Compared to CDC Minimum Standards

Performance Indicator	CDC Standard	South Carolina Performance
Completeness of Reporting	≥85%	98%
Timeliness of Reporting	≥ 66% within 6 months of diagnosis	90%
Accurateness of Reporting	≤ 5% duplicate case counts & ≤5% incorrectly matched reports	0.06% 1.4%
Complete Behavioral Assessment	85% of cases with behavioral risk	66 %

The CDC-funded Supplemental HIV/AIDS Surveillance (SHAS) project conducted 1991 – April 2004 obtained sociodemographic, health care, sex and substance use behaviors, and reproductive health information on newly diagnosed persons with HIV infection in five counties (urban and rural areas). Trained interviewers collected information using a standardized instrument. This project will be replaced by the Morbidity and Risk Behavior Surveillance Project in 2005, which is explained further in this Chapter.

Surveillance staff analyze and disseminate HIV (and other STD's) surveillance data to multiple prevention and care providers, media, community organizations, and others. Surveillance data is used extensively to develop the Epi Profile for HIV prevention community planning; data files are produced for local HIV prevention collaborations for local planning efforts; data by Ryan White service area is produced for care planning. Numerous custom reports are produced for legislators, local agencies, media, and others for grant writing, policy decisions, state health publications, progress reports and program planning and evaluation efforts.

Quarterly STD/HIV/AIDS surveillance reports are completed and posted on the South Carolina Department of Health and Environmental Control web site: http://www.scdhec.net/HS/diseasecont/stdwk/html/surveillance.htm. This web site includes data reports from the Counseling and Testing Sites, and the Supplemental HIV/AIDS Surveillance Project (SHAS). Reports are run for various demographic indicators (age, sex, race, and geographical areas) and behaviors (modes of transmission).

Linkage of Surveillance Data to HIV Prevention Programming

As mentioned above, surveillance data were used extensively by the CPG to determine priority populations, unmet needs, describe risk behaviors, and evaluate specific prevention efforts. These data are reflected through out this prevention plan.

In addition, surveillance data are used to determine prevention and care funding allocations to local health districts, HIV prevention collaborations, and HIV care consortia.

One of the goals of a prevention system is to reach people who may have no knowledge of their risk of HIV infection. A key strategy to reach people is partner counseling and referral (PCRS). Surveillance data are essential to initiate partner counseling and referral services in South Carolina. All newly reported cases are provided to local disease intervention specialist staff for follow-up partner counseling services. Newly reported persons are contacted confidentially and referred for counseling and voluntary partner identification. Named or identified sex and needle-sharing partners are contacted and referred for HIV counseling and testing services.

Many persons contacted, particularly women, have no awareness of their past or current HIV risk or that of their partner. Because they do not perceive their risk, they are unlikely to actively seek information on HIV or get tested. For many persons, the partner counseling and referral process is essential for them to learn of their risk and steps to reduce it, and to learn their HIV status. Counseling and testing data indicate that partners of HIV infected persons consistently have the highest positivity rates (19.3% of partners tested in DHEC clinics were positive in CY 2003), indicating the effectiveness of PCRS in targeting at-risk individuals. Referrals to medical care, support groups, substance use treatment, prevention case management, community-based organizations are provided to clients at the time of PCRS.

Surveillance data, particularly HIV and syphilis are also used to identify counties and areas of highest rates that are used to identify locations for the mobile van screening services.

Finally, pediatric surveillance data on HIV–exposed infants is used by local case managers to refer mothers/infants to the Title IV children's care system, and to monitor if subsequent testing has been done for final HIV status determination. (About 25% of HIV exposed infants will become infected without proper treatment; with treatment the risk drops to 8% or less. Most infants' true HIV status can be determined by 18 months of age.)

New Surveillance Initiatives for 2005

HIV Incidence and Resistance Surveillance

Incidence of HIV infection in the United States, that is, the number of individuals recently infected and diagnosed as having HIV, has not been measured. However, new serologic (blood) testing methods have been developed that distinguish between recent and log-standing HIV-1 infection, which would allow for the determination of national HIV incidence surveillance data. One of these tests is the Serologic Testing Algorithm for Recent HIV Seroconversion, or STARHS. STARHS is an experimental blood test that is part of an Investigational New Drug process overseen by the US Food and Drug Administration (FDA). South Carolina, in collaboration with CDC, is participating in incidence surveillance. Using both the STARHS test and information about a person's HIV testing history, CDC will develop estimates of actual incidence among populations, such as African American women or MSMs. For example, this information will help us try to tell if a person was infected with HIV recently or a long time ago.

Prevention programs can use this data to more effectively target efforts to populations that are recently infected. Incidence data can also be used over time to evaluate the success or impact of prevention efforts in slowing HIV transmission among certain populations.

The HIV incidence project will be introduced in the current South Carolina HIV/AIDS surveillance system in two phases: Phase I STARHS will initiate in January 2005 with persons newly diagnosed and tested through the DHEC Bureaus of Labs. Phase II will be offered by December 2005 to persons newly diagnosed and tested by non-DHEC providers/laboratories.

South Carolina will also be participating in a new surveillance effort by CDC to determine the prevalence of antiretroviral drug resistance (ARVDR) among newly diagnosed persons with HIV infection in public health settings or settings collaborating with public health departments. In 2005, a routine test will be conducted to detect the presence of genetic mutations associated with HIV ARVDR. Clients will designate a clinical caregiver to receive the ARVDRT result which will be used to determine appropriate antiretroviral treatments for the client.

Morbidity and Risk Surveillance Project

South Carolina is one of 20 states selected by CDC to participate in a new surveillance project called Morbidity and Risk Behavior Surveillance starting late 2004 through May 2008. The purpose of the Morbidity and Risk Behavior surveillance project (MRBS) is to develop a supplemental HIV/AIDS surveillance system that will produce population-based estimates of characteristics of persons with HIV infection and the care they receive. This supplemental data will provide essential information needed by HIV care and prevention providers in South Carolina to understand the provision and impact of treatments for HIV, health care utilization, ongoing HIV risk behaviors, care seeking behaviors, quality of life for persons with HIV infection and acceptance of and adherence to prescribed antiretroviral therapy.

These data will also be very important to assist in evaluation of CDC's new prevention initiatives required by state health departments and Ryan White care providers to provide prevention services to persons living with HIV. Data will be obtained through medical record abstractions and patient interviews on a randomly selected national probability sample of approximately 400 persons annually. Both prevention and care providers will use patient interview information on risk behaviors and care-seeking behaviors to enhance current profiles or descriptions of our priority populations and incorporate in the SC HIV Prevention and Care Services Plan. Prevention staff will also incorporate project data in state/regional prevention program evaluation efforts.

Recharacterization of NIR's

In the 2002 – 2004 SC HIV Prevention Plan, one of the surveillance needs described was to create a mechanism to better characterize heterosexual transmission cases and reduce the high number of cases with a "no identified risk" (NIR) category. In April 2004, DHEC surveillance staff began recording risk information beyond the CDC-defined risk categories. The list of risks documented are:

- Sexual intercourse with an infected person of the opposite sex
- Heterosexual prostitution (sex work or exchange of sex for money or drugs)
- Sexual contact with a prostitute of the opposite sex

- Multiple sex partners of the opposite sex (three or more partners after 1977 and before first HIV positive test)
- Sexually transmitted disease
- Crack/cocaine use
- Immigration from a country where heterosexual transmission of HIV predominates

This data will provide more insights on risks among persons with HIV determined as NIR by CDC; additionally, it will provide further risk information on the cases with a CDC-defined risk, such as a person with MSM risk and who also reports crack/cocaine use. All risk information collected is based on client-self report or provider information.

Additional Surveillance Needs

The HIV community planning group, HIV prevention and care providers, and STD/HIV health department staff have identified the following priority supplemental surveillance needs in order to improve the prevention and care planning process, delivery of interventions, and evaluation of overall prevention and care efforts. The priority areas are:

- Behavioral Surveillance among HIV infected and Non-infected Populations
- Estimating HIV Incidence
- Clinical Outcomes

Behavioral Surveillance among HIV infected and Non-infected Populations

A top priority need remains collecting behavioral data for HIV infected and non-infected priority populations. Behavioral information needed among HIV infected persons includes risk behaviors (sexual and drug-related); use of prevention services; access-to-care issues (medical care, sources of payment); types of partners; HIV testing history; identification of venues frequented and adherence to medications. South Carolina will rely largely on the three new surveillance activities described above to obtain this data (Morbidity and Risk Behavior Surveillance project, HIV incidence, and the recharacterization of NIR's).

Behavioral data needed for non-infected priority populations includes risk behaviors (sexual, drug related); use of prevention services; HIV testing history; types of partners; identification of venues frequented, and education to prevent HIV infection. South Carolina DHEC will rely on several data sources to obtain behavioral information for non-infected persons:

- Partner notification interview data among HIV partners and syphilis cases
- Behavioral assessment surveys conducted by organizations conducting community based HIV counseling and testing
- Revised CDC-defined risk data for HIV counseling and testing sites (this will include more information about substance use, types of partners, sexual risks, housing status, etc. than currently collected). This data will begin to be collected July 2005.

In addition, DHEC will use the CDC-sponsored behavioral surveys of youth and adult populations:

- Youth Risk Behavior Surveillance survey data among high-school age youth (includes information about condom use, sexual activity and substance use among sample of South Carolina students)

- Behavioral Risk Factor Surveillance survey data among randomized sample of South Carolina adults through telephone interviews (includes information about HIV testing behavior, knowledge of HIV prevention and treatment, and limited risk behavior data).

Estimating HIV Incidence

Surveillance staff have identified a priority technical assistance need to facilitate HIV incidence estimation. This includes developing statistical models for estimation, introduction to STARHS test and methods for estimating incidence using HIV incidence surveillance data. South Carolina will obtain this technical assistance from CDC.

Clinical Outcomes

Collection of clinical outcomes data for persons with HIV/AIDS is also an identified supplemental surveillance need. This data includes health care utilization (frequency, continuity of care); laboratory data (CD4, viral load tests); prevalence of antiretroviral resistance, immunization and prophylactic services; opportunistic infections; prescription and adherence to antiretroviral medications. Clinical outcomes data will be essential to better evaluate Ryan White care services, meet HRSA reporting requirements, estimate unmet care needs and identify care and treatment training/technical assistance needs. South Carolina will rely largely on the Morbidity and Risk Surveillance project and Resistance Surveillance initiative to obtain this data.

Emerging Populations

In addition to the above priority supplemental surveillance data needs, there is a need to obtain more information about the prevalence of HIV infection and risk behaviors among Hispanic/Latino populations in South Carolina, which is identified as an emerging population. Periodic HIV testing among Latino populations in clinic and community settings will assist in obtaining more data.

2. Research

Learning More About Our Populations and Program Effectiveness

Research in this Plan is defined as activities to acquire information and knowledge to provide further insights and descriptions of systems, provider and population needs which is used to guide planning and programming for more effective HIV prevention services. Research is not defined here as scientific research to determine cause-effect relationships.

A review of the recently updated epi-profile indicates a continued apparent decline in new HIV cases among injecting drug users (70 cases were diagnosed in 2001 vs 41 in 2003). Also of note, is an apparent decline in the number and rate among African American men: the rate per 100,000 population in 2001 was 94.1 vs 72.4 in 2003. African American men had the greatest

decline in annual rate of new cases diagnosed. It is not known if this is truly declining prevalence/incidence or a reflection of a decline in testing among these populations. Particularly among African American men, prevention experts believe many are not accessing HIV testing services due to fears of stigma and discrimination. Prevention program efforts to more effectively reach these populations are needed along with strong program research and evaluation to determine the impact of programs to successfully reach these populations.

During the next three years, three broad areas for research are listed below with key questions. These questions reflect the needs identified by the CPG, DHEC and prevention providers as a result of completing priority setting and needs assessments for this Plan. It is expected that CDC/NIH demonstration project results, literature reviews, and enhanced surveillance efforts, needs assessments and evaluation efforts in South Carolina will focus on answering these questions.

1. Intervention Effectiveness Research

- What interventions are most effective in changing HIV risk behaviors for each of our priority populations?

- How does intervention effectiveness vary in terms of race/ethnicity, sexual orientation, age and other diversity?

2. Research on the HIV Epidemic in South Carolina

- What is the estimated incidence of HIV infection among our priority populations?

- What is the estimated prevalence of risk behaviors among our priority populations?

- Which identifiable subpopulations within MSM, at-risk heterosexual, and IDU populations are most at risk of becoming infected with HIV and should be targeted with prevention interventions?

- How is the overall rate of HIV infection changing? How does this vary by race/ethnicity, age, sex and county of residence?

3. Research on HIV Prevention Programming in South Carolina

- According to our priority populations, what are the best mechanisms to reach and attract them to our services?

- What are the social networks of our priority populations and in what locations do they interact?
- What are the locations of high –risk behavior and how would we conduct our services at or near these locations?
- According to our priority populations, what assets or strengths do they have to support prevention efforts in their communities?
- According to our priority populations, what life circumstances have led them to HIV infection?
- What proportion of our priority populations have been reached by specific interventions?
- What proportion of our priority populations have been referred and successfully linked to other primary and secondary prevention services?
- What are the technical assistance/training needs of our prevention providers?
- How effective is our comprehensive prevention system in impacting changes in knowledge, behaviors and HIV transmission?
- How would we develop an outcome monitoring system to evaluate the effectiveness of prevention interventions on our populations?

Key Recommendations for Surveillance and Research:

Improve the prevention and care planning process, delivery of interventions, and evaluation of overall prevention and care efforts through conducting supplemental surveillance efforts for :

- Behavioral Surveillance among HIV infected and Non-infected Populations
- Estimating HIV Incidence
- Clinical Outcomes

Ensure that the community planning needs assessment process and prevention interventions address the framework of research questions listed.